CHAPTER III.7. COST OF CEREBRAL PALSY

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CHAPTER III.7. COST OF CEREBRAL PALSY

III.7.A Background

This chapter contains a discussion of the methods used and the results of estimating the direct medical costs incurred by individuals with cerebral palsy and the results of the analysis.[1] It does not include information on elements such as indirect medical costs, pain and suffering, lost time of unpaid caregivers, etc. The reader is referred to Chapter I.1 for a discussion of the cost estimation methods and cost elements that are relevant to all benefits estimates. In addition, Chapter III.1 contains information regarding the special characteristics of developmental defects, and a list of chemicals that may cause developmental abnormalities.

The costs presented in this chapter were current in the year the chapter was written. They can be updated using inflation factors accessible by clicking on the sidebar at left.

Link to Chapters I.1 and III.1
Link to inflation factors

III.7.A.1 Description

Cerebral palsy is a motor disorder appearing in early childhood that is caused by brain damage (Waitzman et al., 1996).[2] It is the most common movement disorder of childhood and affects approximately one to six children per 1,000 births. The estimate varies considerably because mild cases may not be determined in early childhood, and all cases may be obscured by other developmental disabilities, such as seizures and mental retardation. The most severe cases may result in rapid death and not be detected. When estimates of the incidence of cerebral palsy are based on evaluations in the neonatal period, the occurrence will be underestimated. It is very difficult to identify cerebral palsy during this period by clinical methods, due to the relative immaturity of the nervous system of newborn infants (Oski, 1994).

Both muscle tone and the control of movement are affected in cerebral palsy (Oski, 1994), which leads to a complex array of movement, posture, and communication problems. Various types of cerebral palsy include athetoid (15 percent of cases), spastic (70 percent), and ataxic (5 percent). Approximately 15 percent of cases are mixed (Wollack et al., 1991).

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[1] "Costs" in this chapter refer to direct incremental per capita medical costs, unless otherwise noted.

[2] Cerebral palsy is often used synonymously with static encephalopathy (Oski, 1994).

Cerebral palsy may affect one or more limbs. Athetoid cerebral palsy patients exhibit uncoordinated and uncontrolled movements. Spastic cerebral palsy patients exhibit exaggerated reflexes, increased muscle tone, weakness, and joint contractures (spasms). Ataxic cerebral palsy patients often have difficulty performing repetitive movements and have a wide-based gait (Waitzman et al., 1996).

Individuals affected with this disorder are among the most handicapped in our society. Although the incidence declined in the 1960s due to better pre- and perinatal care, the incidence has increased in recent years due to the improvement in survival among low birth weight infants. Cerebral palsy usually originates in the pre- or perinatal period; however, it can be brought on in childhood by infection, trauma, and other causes (Oski, 1994).

III.7.A.2 Concurrent Effects

Approximately 21 percent of children with cerebral palsy have malformations unrelated to cerebral palsy; however, no specific occurrence patterns have been reported for major malformations. Occurrences of hip dislocation, curvature of the spine, and poorly developed dental enamel have been frequently reported (Waitzman et al., 1996). About 50 percent of children with cerebral palsy also have strabismus. Depending on the nature of the cerebral palsy, children may have severe retardation, frequent seizures, and blindness, or have a normal intellect with minimal non-motor effects (Oski, 1994).

Other central nervous system (CNS) disorders are common in children with cerebral palsy. Epilepsy occurs in 22 to 50 percent of children with cerebral palsy, increasing with the number of limbs affected. Approximately 25 percent of the children have severe or profound mental retardation, with the degree of retardation generally related to the severity of cerebral palsy. Most children with all limbs affected are severely retarded. Other CNS disorders include severe hearing and visual impairments and speech disorders (Waitzman et al., 1996).

III.7.A.3 Causality

Risk factors for cerebral palsy include the presence of other malformations, maternal retardation, premature separation, low weight of the placenta, breech birth, and low birth weight (Waitzman et al., 1996), although these were more prominent causes in the past, when management of pregnancy and delivery were less refined. Today most cerebral palsy occurs without

identifiable risk factors (Oski, 1994). Table III.1-1 in Chapter III.1 lists numerous chemicals associated with developmental abnormalities in human and/or animal studies.

Link to Chapter III.1, Table III.1-1

III.7.A.4 Treatment and Services

Treatment of cerebral palsy focuses on improving the quality of life and function of the individual. There is no "cure". Surgery on muscles, limbs, and associated sites may be used to restore balance. Brain surgery may be used to reduce spasticity, but may have undesirable consequences. Appliances may include provision of wheelchairs, walkers, casts, or splints. In some cases, medication is used (Waitzman et al., 1996).

Treatment objectives change as the individual ages (Oski, 1994). In early childhood, improving communication abilities is often the focus because these abilities are more closely related than motor function to long-term outcome. In some cases, when speech is not possible, other supportive materials are provided to facilitate communication. Other areas of significant effort are development of the ability to perform basic daily living activities and improving motor skills (Oski, 1994). Treatment of cerebral palsy is rapidly changing and many options are usually offered, often involving multiple medical and educational specialists. Treatment plans are often complex and may require extensive non-medical care, including considerable assistance in day-to-day living activities. These are not a part of the direct medical costs, but they may contribute substantially to the overall costs associated with this disorder.

III.7.A.5 Prognosis

Among those with average or above intelligence (IQ $\geq$ 80), the limitations are not generally severe. Approximately 39 percent are able to function independently as adults, and 48 percent are partially dependent. Of those with lower intelligence, only 1 percent are independent and 17 percent are partially dependent (Cohen and Kohn, 1979). The balance of both the average and below-average intelligence groups are totally dependent. Other issues related to this disorder are low self-esteem and difficulty with sexual relationships. Among those with severe retardation (IQ $\leq$ 50) there is a mortality rate of 28 percent during the first 20 years of life. This is compared to 2 percent among those with higher IQs (Hutton et al., 1994).

III.7.B Costs of Treatment and Services

III.7.B.1 Methodology

Chapters III.3 through III.8 of this handbook use cost of illness estimates developed primarily by Waitzman et al. (1996). Waitzman et al. used the same methodology to estimate the costs incurred by individuals with cerebral palsy as for all the birth defects for which they estimated costs. The methodology and relevant considerations are detailed in Chapter III.3, including discussions of direct and indirect costs, prevalence versus incidence, incremental costs, and concurrent effects. The analytic method, the sources of data, and the limitations of the Waitzman et al. method are also discussed in Chapter III.3. The methodology is outlined briefly here.

Link to Chapter III.3

To estimate the lifetime medical costs incurred by an individual with a birth defect, Waitzman et al. estimated the average lifetime medical costs for an individual with the birth defect. From this value, the authors subtracted the average lifetime medical costs for an individual without the birth defect. Because they estimated lifetime costs, they used an incidence-based approach. Ideally, they would have tracked the costs of the cohort members over time, until the death of the last cohort member. Because the members of the cohort were born in 1988, however, this tracking was not possible. Instead, estimates of the costs incurred at each age were based on estimates of per capita costs in the prevalent population of that age (see Chapter III.3, Section III.3.B.1.2).

Link to Chapter III.3, Section III.3.B.1.2

This method has two important implications. First, Waitzman et al. estimated the costs incurred by individuals with birth defects, including all medical costs incurred, rather than the cost of the birth defect per se. These cost estimates therefore include the costs of concurrent effects (unlike the costs reported for many of the diseases in this handbook). This method yields a more comprehensive assessment of total costs than would be obtained if only individual effects were evaluated. This method is of particular use in valuing the avoidance of birth defects because they very frequently occur in clusters within an individual. As Waitzman et al. note, however, the costs of associated anomalies are included as part of the estimate of the costs incurred by an individual with a given birth defect. These cost estimates therefore cannot be aggregated across birth defects because of the possibility of double counting.

Second, the Waitzman et al. method estimates the *incremental* costs for individuals with birth defects — that is, the costs above and beyond the average costs that would be incurred by individuals without the birth defect.

Waitzman et al. (1996) estimated three categories of costs incurred by individuals with limb reductions: direct medical costs, direct nonmedical costs, and indirect costs.[3] Direct medical costs, specifically inpatient care, outpatient care, pharmaceuticals, laboratory tests, X-rays, appliances, and long-term care are included in the cost estimates shown in this and other chapters (Chapters III.3 through III.8) based on the work of Waitzman et al. Nonmedical direct costs, specifically developmental services, and special education are also included in this handbook.

The Waitzman estimates of the costs incurred by individuals with limb reductions are based on the costs of this birth defect in California across many ages, and its occurrence in a large cohort of children born in California in 1988. California's ongoing birth defects monitoring program provides an excellent source of data. The California data sets were linked with other national data sets so that Waitzman et al. could estimate the incremental costs associated with cerebral palsy.

The method of calculating the expected lifetime incremental costs for an individual with a birth defect — i.e., the average lifetime cost per case — is the same for all the birth defects considered by Waitzman et al. The expected per capita cost at age *i*, PCC_i, for an individual born with the birth defect is the probability of surviving to age *i* (among those individuals born with the birth defect), ps_i, times the per capita cost among individuals who do survive to age *i* ($PCPREV_i$, measured in the prevalent population):

$$PCC_i = (ps_i) \times (PCPREV_i) .$$

Waitzman et al. estimate per capita costs in the prevalent population of age *i*, $PCPREV_i$, in two different ways, depending on data availability (see Chapter III.3).

Link to Chapter III.3

The present discounted value of expected per capita lifetime costs of the birth defect, PCCOBD, is just the sum of these expected age-specific per capita costs, appropriately discounted (as explained more fully in Chapter III.3):

$$PCCOBD = \sum_i PCC_i/(1+r)^i .$$

[3] Indirect costs are not generally discussed in this handbook and so are not included in this chapter. The reader may wish to consult Waitzman et al. (1996) for information on these costs.

III.7.B.2 Results

Waitzman et al.'s (1996) estimates of the total lifetime medical costs of cerebral palsy are outlined in the following tables. Estimates are updated from 1988 to 1996 dollars based on the medical care cost component of the Consumer Price Index (1996:1988=1.6465). Table III.7-1 shows the annual per capita medical costs incurred by individuals with cerebral palsy by age group.

Table III.7-1: Annual Per-Capita Medical Costs of Cerebral Palsy by Age Group (1996$)

Condition	Age 0-1	Age 2-4	Age 5-17	Age 18+
Cerebral Palsy	$16,236	$9,848	$11,451	$19,349

The medical cost of the average population was then subtracted from these costs to obtain incremental costs. Waitzman et al. (1996) discounted these costs using three different discount rates: two percent, five percent, and ten percent. Although these discount rates do not match the standard EPA rates used in many other chapters in this handbook (zero percent, three percent, five percent, and seven percent), there is insufficient information provided in Waitzman et al. (1996) to allow a conversion to discounted costs using standard EPA discount rates. This problem exists in all chapters based on the Waitzman et al. data (i.e., Chapters III.3 through III.8).

The present discounted values of average per capita lifetime incremental costs, using discount rates of two percent, five percent, and seven percent, are listed in Table III.7-2 below. Direct medical costs and direct non-medical costs are listed separately. The sum of per-capita direct medical and nonmedical costs provides an estimate of the total per-capita costs incurred by individuals with cerebral palsy.

Table III.7-2: Per-Capita Net Medical Costs, Nonmedical Costs, and Total Costs of Cerebral Palsy (1996$)			
Cost Element	**2%**	**5%**	**10%**
Net direct medical costs	$461,010	$233,798	$116,899
Net direct nonmedical costs			
Developmental Services	$145,106	$68,979	$30,853
Special Education	$94,454	$71,771	$47,634
Total Costs	$700,570	$374,548	$195,386

The costs presented in this chapter were current in the year the chapter was written. They can be updated using inflation factors accessible by clicking below.

Link to inflation factors

III.7.B.3 Other Studies

Waitzman et al. (1996) present a study conducted in 1991 by The National Foundation for Brain Research (NFBR), using a prevalence approach, on the cost of cerebral palsy. Rather than using the primary diagnosis, however, to construct costs (as in Rice et al., discussed in Chapter III.3), cost estimates were made for cerebral palsy appearing as the first through fifth diagnosis for inpatient stays, and the first through third diagnosis for physician visits. The NFBR also estimated indirect family costs based on family income reported in the 1989 National Health Interview Survey. Waitzman et al. compare their estimate for direct medical costs of $172 million, adjusted to the nation and 1991 dollars, to the NFBR estimate for inpatient stays of $318 million. They identify two reasons for the difference in these two estimates. First, an incidence approach, such as the approach used by Waitzman et al., uses discounting, whereas a prevalence approach, such as that used by NFBR, does not. For example, Waitzman et al. calculate that the 1991 estimate of $172 million discounted at five percent would increase by over $100 million to $282 million if a two percent discount rate was used instead. Second, Waitzman et al. estimate incremental costs by subtracting the average costs of an individual without cerebral palsy, whereas the NFBR study does not subtract average costs. Waitzman et al. show that had they not subtracted the average costs, their estimate for cerebral palsy in 1991 at a five percent discount rate would be $330 million, an estimate much closer to the one produced by the NFBR study.

Link to Chapter III.3

III.7.C Conclusions

The cost estimates based on the research by Waitzman et al. (1996) are recommended for use in benefits valuation. The NFBR study does not include many relevant medical costs (including all non-hospital costs). They also do not use an incremental approach. Consequently, the NFBR cost estimates are not as closely matched to the direct medical costs which are reported in this handbook as the Waitzman et al. results.